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ABSTRACT

A study was conducted to examine young children's ideas about a psychology study in which they had participated, and to assess their perceptions about the voluntary nature of their participation. Subjects were 28 third-grade students and 28 fifth-grade students. Findings indicated that while no significant grade level differences existed in students' understanding of the purposes of the research, the responses of a sizable minority of third graders would not meet Weithorn's (1982, 1984) criteria for informed consent. Age and gender differences were found concerning ideas about withdrawing from the research. Although a majority of children at both grade levels felt they could withdraw, more girls felt that withdrawing was acceptable. Age differences were found in reasons for not withdrawing. Younger children spoke about enjoying the experience, whereas older children spoke of guilt or issues of commitment. It is concluded that, although children may be able to agree to participate in research by virtue of their knowledge about a study and its purposes, they may feel less free to withdraw. Decisions about withdrawing from research studies may have less to do with issues of boredom or discomfort and may be more directly related to moral development or understanding of contractual agreements. (RH)

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Children's Understanding of Their Participation in Psychological Research

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Children's Understanding of Their Participation in Psychological Research

Historically, minors had little or no standing in the eyes of the law. Because of that, the issue of obtaining an agreement from minors to participate in research was somewhat moot. With psychologists' greater understanding of child development, particularly cognitive development, it is clear that children and adolescents understand much about what they are doing. Many psychologists now believe that children and adolescents should be a part of the decision- making process concerning participation in research. This belief led to the study of children's ability to consent and assent.

The study of consent and assent primarily focused on children's ideas about their medical or psychological treatments (e.g., Dollinger & Thelen, 1978; Susman et al., 1982). A smaller number of researchers have investigated children's decision-making capacities (e.g., Melton, 1980; Weithorn & Campbell, 1982) and decision-making processes with regard to undergoing treatment (e.g., Lewis, 1983). Although Weithorn (1984) argued that consent in the research and treatment contexts were similar, there may be reason to believe that the decision-making process for participating in psychology research differs from the decision-making process for clinical or biomedical research. Three important differences between the two contexts come to mind. First, biomedical and clinical research involve the rendering of a service presumed to be helpful (if not life-saving) to the participant, whereas the "benefits to the participants" in psychology research are usually less dramatic (if immediately discernible at all).

A second important difference is the degree of stress the participant and his or her family is experiencing when confronted with the decision concerning participation. A good deal of psychological research presumes that the participants are "normal," that is, experiencing no undue external pressures. In fact, being in a situation that might be causing the person to be highly stressed at the time of the research may be sufficient reason to disqualify a person's participation in the research. The person might be too different from other participants and therefore not representative of the sample. In biomedical and clinical research participants are presumably in some kind of physical or emotional state that needs relief or intervention. Therefore, participants are more likely to be stressed and more vulnerable to agree to participate when asked. They may be in a kind of "I'll try anything" state, hence their evaluations of the research may not be fully informed.

Finally, the degree of discomfort of procedures differs between biomedical and psychological research. Biomedical research often involves subjecting participants to painful procedures. If such pain were inflicted in most psychological research, it is doubtful the proposed research would clear a human subjects institutional review board. Because of these three differences it is reasonable to investigate the decisions to participate in psychological research separately from decisions regarding medical research.

At present there is consensus that children as young as seven years are capable of giving assent. That is, they can understand at a basic level what will be done to them or what they will be required to do. They are also able to understand the basic purposes of the research (Weithorn, 1984). Several studies of children between ages 7 and 14 demonstrate that children do

consider meaningful elements when choosing whether to participate in either actual biomedical research (Lewis, Lewis, & Ifekwunigue, 1978) or hypothetical research studies (Keith-Spiegel & Maas, 1981; Weithorn & Campbell, 1982). However, the understanding of actual psychological research in which children have participated has yet to be fully explored.

One of the major distinctions between assent and consent is that in consent one presumes the ability to evaluate the information provided concerning the nature of the study, the risks, and the benefits. Part of this process includes a recognition that one is free to refuse to participate and is free to withdraw from the procedures once participation has begun. Although we do not assume that children are capable of making such evaluations, we often make the implicit assumption that they know they do not have to participate and they are free to stop. However, as has been pointed out by others (e.g., Keith-Spiegel, 1976, and Koocher, 1983), for children, agreeing to participate in research may be less voluntary since it is ingrained in children that they should do what adults ask of them. In addition, withdrawing from research may not be viewed as an option since it may be considered noncompliant behavior which is highly discouraged among children. The extent to which children feel the freedom to dissent or withdraw from research is not well explored.

The purpose of the present research was: 1) to examine young children's ideas about a psychology study in which they participated; and 2) to assess their perceptions about the "voluntary nature" of their participation.

Method

Twenty-eight third graders and 28 fifth graders participated in the study. These children were participating in dissertation research conducted by James Van Haneghan of the University of Maryland Baltimore County. Dr. Van Haneghan's study was designed to examine children's ability to recognize errors and unsolvability of mathematical word problems. At the completion of their participation in Dr. Van Haneghan's study, children were asked if they would answer some general questions about the study (we labeled this as the "debriefing interview").

Two different sets of interviews were given. One set of questions related to children's understanding of the research process. The second set of questions dealt with notions about the voluntary nature of the research process. Children only were interviewed on one set of questions. Although future research should interview the same children on both sets of questions, in the present instance we felt that two interviews in addition to their participation in the original study would be too time consuming given that children were being taken out of their regular classes for the study. The interviews were alternated so that after the original study every other child was asked about research and every other child was asked about the voluntary nature of the study. The two groups did not differ on their ability to successfully complete the original math study.

All debriefing interviews were tape recorded and verbatim transcripts were made for the purposes of coding. Coding criteria were developed to categorize the types of responses given by the children. Interviews were coded by someone unfamiliar with the hypotheses of the study and were recoded

by a second rater, also naive to the hypotheses of the study. Reliabilities were based on percent agreement between raters. Reliability for the questions concerning the understanding of research ranged from 67% to 100%, $\bar{X}$ = 79%, and for the understanding of the voluntary nature of the study ranged from 74% to 96%, $\bar{X}$ = 88%.

Understanding Research

Fifteen third graders and 14 fifth graders were asked about the research process. Five basic questions were asked along with follow-up probes which helped to clarify or elaborate the children's responses. The basic questions were:

1) How come I go around asking children to do math problems?
2) How come I need to talk to so many different children?
3) Do you think I'm asking everyone the same problems or different problems?
4) Do you think I know the answers to the questions that I asked you?
5) I told you before I was doing a study/research to learn how children solve math problems. I was wondering, what's a study/research?

As expected, there were no significant sex differences in responses. Therefore, responses of boys and girls were pooled.

Two-thirds of the third and all fifth graders agreed that the experimenter asked them to do the problems to learn something about how children do math problems. This is consistent with what was explained in the consent form. One-third of the third graders, however, explained that this was a chance to help children with their math skills. Hence their understanding of the situation was educational and for <u>their</u> benefit rather

than exploratory and for the researcher's or science's benefit. Thus, although these children understood what is being done to them (one aspect of assent as defined by Weithorn), they did not understand the basic purpose of the research. As will be suggested later, this misunderstanding may have strong implications for children's feeling free to withdraw from the research.

Third and fifth graders did not differ on their understanding of why so many children need be involved, nor on their ideas of whether their answers would differ from the investigator's. However, of note is that a majority of children's responses at each grade level suggested that their answers would differ from the experimenter's. Reasons for this were acknowledgement that the experimenter is smarter, makes fewer errors or just thinks differently from the child. Although I have not figured out what to make of this finding, it leaves me with an unsettled feeling that many children assume they failed or did not do well on the math problems. It does suggest a need to talk with children after their participation to learn how they would assess their performances and to deal with any negative feelings they may have about their performances.

Finally, third and fifth graders differed on their understanding of "what is a study or research?" Almost all responses by fifth graders involved notions that one is trying to find something out; only 25% of the third graders gave that kind of response. Many third graders claimed they did not know, or it was when you practiced something. Again, this suggests that the younger children are not really aware of the circumstances of their involvement.

Voluntary Nature

Thirteen third graders and 14 fifth graders were asked about the voluntary nature of their participation. Five basic questions were asked along with follow-up probes which helped to clarify or elaborate the children's responses. The 5 basic questions included:

1) Whose idea was it that you participate in this study?

2) What would have happened if you said "No"?

3) Would it be okay to stop and not finish?

4) What would have happened if you stopped working on the problems?

5) Why didn't you stop?

Again, as expected, there were no significant sex differences in responses. Therefore, responses of boys and girls were pooled.

There were no significant differences between the third and fifth graders' responses concerning whose idea it was to participate. Almost all the children at each grade felt that the decision to participate was either entirely their own or their own in collaboration with their parents. In addition, most of the children at both grade levels felt that no one would be angry if they chose not to participate. Children appear to genuinely feel they have some say in their decisions to participate in research.

Where there was greater variability of responses was in the consequences of their behaviors. The reasons for agreeing to participate and for not withdrawing differed with age. Thirty percent of the third graders felt that their refusal to participate would have meant a missed opportunity to learn something, whereas all but one of the fifth graders saw no consequences for their lack of participation. A similar pattern is seen when asked about the

consequences for not continuing in the study. Two-thirds of the third graders felt it would not be okay to stop once they began their participation. They cited concern about others' reactions and not getting help in math as consequences for stopping.

By contrast, only 23% of the fifth graders felt that there would be a consequence were they to withdraw from the study. Thus, once agreeing to participate, concerns about noncompliance does seem to be a greater issue for the younger participants. Younger children, even if able to agree to participate, are less likely to feel a "freedom to withdraw." This finding suggests that the younger the participants, the more sensitive we need to be in assessing nonverbal signs of discomfort or disinterest.

In fact, though, all children who reached the stage of the debriefing interviews did complete their participation in the study. For the most part, reasons for not stopping had less to do with expectations of consequences and more to do with the nature of the task. Fifty-seven percent of the third graders and 64% of the fifth graders explained that they finished the problems because they enjoyed the task or it was easy. This speaks to the importance of researchers creating a compelling task in order to keep their young participants engaged. This finding also suggests a potential difference between agreeing to participate in psychology and medical research. My experience with children's roles in medical research is that very little could be described as "fun."

A sizable minority (28%) of the fifth graders mentioned that the reasons for continuing to participate were more out of a personal sense of obligation, that is, "I finish what I start." Only one third grader gave this response.

This suggests that by fifth grade, a sizable minority of children begins to take their commitments more seriously. Continuation of participation, though still heavily based on the pleasure or enjoyment of the task, begin to be seen in terms of a moral commitment, a contract between child and experimenter. This may be a result of children's transition from heteronomous to autonomous morality (Piaget, 1932/1962).

Discussion

It is important to learn how children understand the research and consent/assent processes. However, investigating these questions poses an ethical dilemma in itself. All interviews in the present study were completed by children who agreed to participate in the research (and whose parents consented). What about those who refused to participate? We know nothing about whether refusal is based on adequate understanding of the research and the research process. For instance, it may be that those who refused did not recognize that once they began the study they could withdraw. In order to know if informed decisions are being made, it is important to learn if non-participants are equally capable of making an informed decision. Yet this issue cannot systematically be explored because the researcher ethically cannot question those who refuse to participate in research.

However, the present method of studying research participants does allow us to learn whether the rights of our research participants have been maintained. It may be useful to know whether those who refuse participation are informed adequately. This might tell us whether we could increase participation through more adequate preparation and briefing of potential participants. However, from an ethical point of view, a person has the right

to make what Keith Spiegel (1976) called "uninformed dissent." The issue of informed or uninformed dissent may only be important in clinical or biomedical research when refusing a treatment may lead to the withholding of a potentially therapeutic treatment.

The issue of how children actually understand research is important both because of questions about assent and in terms of evaluating the voluntary nature of participation. In the present study, one-third of the third graders believed the research was to help them learn math. Thirty percent of the third graders explained that if they had refused to participate in the study they would have missed an opportunity to learn. Although a minority viewpoint, this is still a significant minority. If children view the research as a chance for them to learn something (e.g., here, math skills), rather than as an endeavor for the researcher to learn something, then children may feel greater pressure to participate and not withdraw, even when they want to quit. Not only are children primed to listen to adults (Keith Spiegel, 1983), they are told that learning is important. Adequate understanding of the process of research, that is, understanding that it is the experimenter who is trying to learn something, may make it easier for young children to evaluate whether or not to participate.

In general, results of the present study support research concerning children's ideas about participation in biomedical research. Most of the children in both grades understood the basic purpose of the research and most believed they had some part in the decision making process. Despite this, there is still a sizable minority of third graders (approximately 9 years old) who would not meet Weithorn's two criteria for informed assent because they

would not have a general understanding of the purpose of the research. This finding does suggest the need for added care and sensitivity to younger research participants. One concrete thing we can do as researchers is to spend a little more time with younger children in explaining why we are doing our research. We need to do so in a way that puts the responsibility for new learning on our own shoulders not the children's shoulders.

Many older children in the present context based their decisions to continue on more moral grounds, that is, "I finish what I start" or "I said I'd do this." If decisions to withdraw from psychological research constitute moral dilemmas for children, then we can borrow from our knowledge of moral development to anticipate children's reactions. That is, we could anticipate that young children (at lower moral levels) would fear negative consequences were they to withdraw, whereas children at higher levels might be more concerned with their own commitments to the researchers or impeding the acquisition of scientific knowledge. Our knowing what may be potential obstacles to withdrawal can help us learn where we need to be particularly sensitive to children.

Finally, the results of the present study support the notion that there is a difference between decisions to participate in psychology or medical research. A task perceived as "fun" as opposed to a treatment perceived as "painful" may influence one's decision to withdraw from the research once it has begun. It also is possible that the potential of receiving important therapeutic treatments may be more compelling than once thought and provide too great an enticement, thereby obfuscating the decision making process.

At present many of our ideas in psychological research concerning issues of assent/consent and the treatment of research participants are based on work pertinent to medical research, therapeutic interventions, and hypothetical situations. We need to know more about participation in actual psychological research to decide how to modify or expand our policies concerning consent and assent to reflect the realities of the context.

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